The Report Committee for Brittney Wolf
Certifies that this is the approved version of the following report:

Surveying the Communication Needs of Adolescents and Young Adults with Autism: Implications for Transition Planning

APPROVED BY
SUPERVISING COMMITTEE:

Supervisor:

Barbara Davis

Jessica Franco

Surveying the Communication Needs of Adolescents and Young Adults with Autism: Implications for Transition Planning

by

Brittney Wolf, B.S.

Report

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Brittney Wolf, MA

The University of Texas at Austin, 2013

Supervisor: Barbara Davis

Research has shown that the majority of young adults with autism achieve poor-fair outcomes. It is known that communication deficits in individuals with autism may persist throughout the lifespan. However, there is a paucity of information in the literature pertaining to the communication needs of adolescents and young adults with autism. To meet the complex needs of these individuals, transition plans and programs must be improved. One way in which transition programs can be improved is by incorporating evidence based assessment and intervention methods designed for this population that target communication skills. Caregivers (n=68) of adolescents and young adults with autism anonymously completed a survey pertaining to outcomes, goals, and communication skills. Outcomes for the young adults were mostly poor and communication skill performance was variable. Results revealed that overall, caregivers perceived some communication skills to be more important than others. Caregivers rated the importance of communication skills differently depending on the social goals of the individual with autism. Results achieved significance for the relationship between developmental language level and the

perceived importance of certain communication skills. Findings demonstrate that specific communication skills should be assessed and targeted during transitional planning for individuals with autism.

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CHAPTER 1: INTRODUCTION

There is growing recognition that adolescents and young adults with autism need support in order to transition effectively from secondary education to employment (Cheak-Zamora, et al., 2013; Schall et al., 2012). Transition services have been defined within the Individuals with Disabilities of Education Act (IDEA) 2004 as "a coordinated set of activities for a child with a disability that is designed to be a results oriented process, that is focused on improving the academic and functional achievement of the child's movement from school to post-school activities"(IDEA; 2004 [[602(34)(A)]]. Within this process, students, parents, teachers, and other professionals are required to develop an Individualized Education Plan (IEP) that considers the needs, strengths, weaknesses, and interests of the student. IDEA (2004) mandates that the IEP include measureable goals that are meant to assist the student in achieving their transition goals in the areas of training, education, employment and independent living skills.

Results of outcome studies indicate that individuals with autism may not be consistently provided with skills that will help them successfully transition from high school to work and/or independent living (Gerhardt & Lainer, 2011; Taylor & Seltzer, 2011). These studies demonstrate that transition plans developed under IDEA may not be effective for students with autism (Gerhardt & Lainer, 2011). Individuals with autism who are of transition age have specific needs that are distinct from individuals of other disability groups (Levy, et al., 2011; Schall et al., 2006; Schall et al., 2012). One of the core features of autism spectrum disorder is communication impairment, and the majority of adolescents and young adults with autism exhibit a number of communication deficits

(Seltzer et al., 2003; Sigman & McGovern, 2005). According to the American Speech Language Association (2006), speech-language pathologists play an important role in advancing communication skills that will assist individuals with ASD in achieving greater independence in home, school, work and community environments. Although a number of transition assessments and guidelines have been developed, these assessments are not tailored specifically for individuals with autism and they only include a few broad items related to communication skills (Ansell & Casey Family Programs, 2009; Clark & Patton, 2009). One way in which transition programs can be improved is by incorporating evidence-based assessment methods designed for this population that target communication skills needed for success in postsecondary life. In order to create treatment goals that will assist individuals with autism in accomplishing their larger transition goals, the specific communication needs of this population must be determined. The present study focuses on exploring the communication needs of young adults with autism and the relationship between social goals and specific communication skills. Results will help speech- language pathologists to more effectively address the unique needs of this population.

CHAPTER 2: BACKGROUND

COMMUNICATION CHARACTERISTICS OF ADOLESCENTS AND ADULTS WITH AUTISM

Autism is a neurodevelopmental disorder characterized by core impairments in social interaction, social communication, and behavior (DSM–V: APA, 2013, in press). Communication impairments exhibited by children with autism consist of verbal and nonverbal communication impairments (Mirenda, P., 2009). Great variation exists in the specific communication deficits of children with autism. Many children with autism do not develop verbal speech. Those who do may use echolaic or idiosyncratic speech. In addition, children with autism exhibit deficits in nonverbal communication including inability to demonstrate eye contact or gestures in order to request, participate in joint attention or interact socially (Seltzer et al., 2004; Sigman & McGovern, 2005).

A number of the communication characteristics associated with autism may persist into adulthood (Howlin et al., 2004, Mawhood et al., 2000; Seltzer et al., 2003; Sigman & McGovern, 2005). Several longitudinal studies have been conducted to determine the progression of communication characteristics from early childhood to adulthood. Seltzer and colleagues (2003) provided data regarding the stability of ASD diagnostic profiles throughout the lifespan and changes in communication characteristics associated with autism based on results of the Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 1994). Lifetime scores, which were calculated based on symptoms present at the age of 4-5 years or any time throughout the lifespan, were compared with scores that reflected current presence of symptoms. Results revealed that there were

significant differences between lifetime and current scores in nonverbal and verbal communication, indicating that the participants' verbal and nonverbal communication skills had improved. Specifically, comparison of lifetime and current scores demonstrated that 60% of the sample who could not speak in 2-3 word phrases at the age of 4-5 were currently able to do so at the time of the study. A significant number of verbal individuals no longer utilized pronominal reversal (45.5%) or neologisms or idiosyncratic language (33.8%). On the other hand, the symptom of asking inappropriate questions only abated for 8.5% of the sample. Specific nonverbal communication deficits that persisted for the majority of the sample were impairments in using gestures (i.e., nodding, head shaking) and pointing to express interest. It is important to note that although there was a decrease in the number of individuals with certain communication deficits, there were still a substantial number of individuals exhibiting these deficits. For example, 45.5% (191) of the sample no longer exhibited pronominal reversal, meaning 214 individuals continued to use pronominal reversal.

Sigman and McGovern (2005) also studied changes in verbal and nonverbal communication symptoms from early childhood to adolescence and young adulthood. A 10-year follow up study was conducted in which 48 participants were administered cognitive, language and nonverbal communication assessments during preschool (mean age = 3;11), middle childhood (mean age = 12;8), and young adulthood (mean age = 19;0). Analysis of data from the *Reynell Scales of Language Ability* (Reynell, 1977) indicated there was on average a 28-month language gain from preschool to the middle school period. The *Clinical Evaluation of Language Fundamentals-Revised* (CELF-R;

Semel, Wiig & Secord, 1987) was used in addition to the *Reynell* to measure changes in language abilities from middle school to young adulthood. Results indicated that the 37 participants who received language assessments at these two time periods demonstrated an average language gain of 12 months with a range from -10.5 months to +83 months. Nonverbal communication changes were measured using The *Early Social Communication Scale* (ESCS; Seibert, Hogan, & Mundy, 1982) during the preschool period, and an evidence based modified version was utilized for the middle school and young adulthood assessments. Results revealed that the abilities to initiate joint attention and request appropriately declined from the middle to young adulthood period. The ability to respond to bids for joint attention did not alter from middle childhood to young adulthood, however. These results suggest that services for young children with autism may be effective and that the lack of services available for middle school and high school individuals with autism may be preventing ongoing improvement in communication performance during this period (Sigman & McGovern, 2005).

Similarly, Mawhood and colleagues (2004) found that there was little improvement in communication skills from childhood (mean age 7) to adulthood (mean age 24) for a group of 19 males with autism. The average change in standard scores on the *Peabody Picture Vocabulary Test* (PPVT; Dunn et al., 1997) from childhood to adulthood was only 3.78 points. Subtests focusing on communication on the *Autism Diagnostic Interview-Revised* (ADI-R; Lord et al., 1994) and the *Autism Diagnostic Observation Scale* (ADOS; Lord et al., 2002) were also administered in adulthood to obtain a full representation of the communicative level of the participants. Results

revealed that eight individuals were utilizing "good sentence speech", 5 were using "immature speech", 4 were "mute or using only a few single words", and two were primarily utilizing echolaic speech (Mawhood, et al., 2000, p. 551).

EMPLOYMENT AND SOCIAL OUTCOMES IN AUTISM

A number of outcome studies have been conducted over the past 30 years to explore the lives of young adults with autism spectrum disorder (Levy & Perry, 2011). As there have been many changes to the service system within this time period, studies conducted in the past 10 years, will be reviewed. Several recent studies have focused exclusively on measuring the outcomes of individuals with average or near average cognitive and linguistic abilities and individuals who have been diagnosed with Asperger's Syndrome. The findings of these studies demonstrate that these individuals are more likely to achieve better outcomes in employment, living situation and social life (Cederland et al., 2008; Engström et al., 2003; Gilchrist et al., 2001; Howlin, 2005). Fewer outcomes studies have been conducted which include participants who exhibit the range of cognitive and linguistic abilities characteristic of Autism Spectrum Disorders. Taylor and Seltzer (2011) provided data regarding the employment and day activities of 66 young adults with autism who were recruited as part of their larger longitudinal study. Their sample included individuals who had left high school within the last 3 years. About 75% of the individuals in the sample had been diagnosed with an intellectual disability and 73% were considered verbal as a result of their ability to produce functional 3-word phrases on a daily basis. Findings demonstrated that 13.6% (n=9)

attended college, 6% (n=2) were competitively employed, 12.1% (n=8) had supported employment, 56.1% (n=57) attended adult day services, and 12.1% (n=8) did not attend any regular activities. Adults with autism and concomitant ID were much more likely to attend adult day services than individuals without ID, but only 4% (n=2) of adults with autism and concomitant ID were competitively employed and 12% (n=6) had supported employment.

Billstedt et al. (2005) longitudinally studied 120 Swedish individuals with autism and Asperger's syndrome longitudinally. They found similar results related to the outcomes of individuals with autism. In their study, 79% of the participating individuals in the autism group had an IQ less of less than 70. Level of outcome for each group was determined by the criteria developed by Lotter (Lotter, 1978). Regarding employment outcomes, one man in the autism group was competitively employed, four attended daily occupational activities at a group center, and 33 had individual daily activities and thirteen did not have any daily activities. In the autism group, only 3 males were living independently and they all relied on help from their parents. Based on data from all domains, 5 participants were considered to have a fair outcome, 12 had a restricted outcome, 14 had a poor outcome, and 39 had a very poor outcome within the autism group.

Eaves and Ho (2007) also found poor outcomes related to employment in their study of 48 adolescents with autism born from 1974-1984 in Canada. Of the 48 participants, 61% were diagnosed with autism at a mean age of 11.4, and the other 39% were considered to have atypical PDD, language disorder, or intellectual disability with

autistic characteristics. The participants were interviewed regarding occupation, friendships, and independent living at a mean age of 24. Results of the interviews demonstrated that 50% of the participants had fair-good outcomes and 50% had poor outcomes. Specifically, 27 (56%) individuals had been employed at one point, but only 1 individual worked at a full time job independently. The remainder of the participants worked part-time, in sheltered workshops or had a volunteer position. With regards to living situation, 27 (56%) lived with their parents, 17 (35%) lived in group homes, or foster care, and 4 participants lived independently. The majority of participants (78%) had a government disability pension and received social work services. Day programs were also attended by 40% of the participants and 56% received respite care. Regarding social life, 16% of participants reported having one meaningful friendship, and 85% stated they had a hobby. Better outcomes were achieved by the individuals in this study in the areas of independent living and social life than individuals in the studies reviewed earlier. The authors suggest this outcome may be due to improved educational practices, early identification, and inclusion in schools.

Most recently, Gillepsie-Lynch and colleagues (2012) interviewed the parents of twenty individuals with autism (M=26.6 years) regarding social outcomes. Similar to the findings of the Eaves and Ho (2008) study, participants in their study achieved slightly better outcomes than those reported in previous studies. Of the twenty participants, 4 (20%) achieved a very good outcome, 2 (10%) achieved a good outcome, 3 (15%), and 10 (50%) achieved a poor outcome. The authors noted that the results are considered exploratory in nature due to the small sample.

Overall, poor-fair adult outcomes appear to be common in a number of countries. It is important to note that there have only been a few recent adult outcome studies conducted in the United States. Given that the amount and types of services offered to individuals with autism varies by country, it would seem crucial to consider social outcomes within the United States when exploring the needs of individuals living here.

TRANSITION SERVICES AND SPEECH-LANGUAGE PATHOLOGY

Despite the recognition that speech language pathologists (SLPs) should play a role in transition planning, there are markedly few evidence-based guidelines for working with youth of transition age (Alpern & Zager, 2007; Eskow & Fisher, 2004). It is frequently mentioned that the transition team consists of related service professionals, but there is no information regarding specific responsibilities. There could be several reasons to explain the lack of available evidence-based methods. Results from a nationwide survey revealed that only 7% of SLPs working in the school setting work primarily in secondary schools, and 19% work in both elementary and high schools (ASHA, 2006B). Salley (2012) studied service delivery models used by SLPs employed in the secondary school setting in Virginia. Results of the survey indicated that the majority of SLPs continued to utilize traditional methods, even though research has shown collaborative and consultative models to be more effective and appropriate with the high school population. Also, secondary students may not be referred for speech services because teachers and other professionals working in secondary schools may not be aware of the scope of practice of a SLP (Ehren, 2000).

Additionally, researchers within the field of speech language pathology have typically focused on developing effective assessment and intervention methods for younger children. It should be noted, however, that information in the literature regarding general transition guidelines has only recently grown. In order for SLPs to provide the necessary services for adolescents with communication impairments, they must educate other professionals regarding how speech-language pathologists are best suited to address students' communication needs (Ehren, 2002; Harvell, 2000). Access to more information regarding the communication needs of adolescents with communication impairments will facilitate a process in which SLPs can advocate for students. As mentioned earlier, research has shown that there is greater improvement in communication skills from the early childhood period to the middle school period than from the middle school period to the young adulthood period (Sigman & McGovern, 2005). This outcome demonstrates the need for improved speech therapy services for middle and high school students.

COMMUNICATION NEEDS OF ADOLESCENTS AND YOUNG ADULTS WITH AUTISM

Research documenting the communication characteristics of adolescents and adults in autism demonstrates that communication impairment continues to be a core feature of autism throughout the lifespan. Despite this recognition, there is little information available regarding the communication needs of this population. As Schall & McDonough (2010) point out, the communication needs of a young child with autism

may be different than the needs of an adolescent with autism, even if the adolescent is functioning at a low level socially. Recently, Alpern & Zager (2007) provided guidelines for addressing the communication needs of young adults with high functioning autism in a post-secondary setting. They highlight the importance of considering the individual's current living situation and employment status when providing services for individuals in a post-secondary setting. However, there is little empirical information available regarding the specific communication needs of individuals with autism transitioning to postsecondary life. Researchers studying the transition period for adolescents and young adults with autism have described the importance of developing evidence based methods for assessing and treating this population in order to achieve improved outcomes (Gerhardt & Lainer, 2011; Lounds Taylor J, Dove D, Veenstra-VanderWeele J, et al., 2012; Schall & McDonough, 2010).

CHAPTER 3: PURPOSE

The primary purpose of this study was to explore the specific communication needs of adolescents and adults with autism who are transitioning from secondary schooling to postsecondary life. This information will be gathered from the perspective of their caregivers. The second purpose was to determine how the adolescents' communication needs relate to larger goals in the areas of their living situation, social life, and employment. We hypothesized that there would be differences between survey responses of individuals with different larger goals. Although it is well known that adolescents and young adults with autism exhibit a range of communication deficits, it is unknown which specific communication skills are most essential in order for them achieve their goals. We hypothesized that caregivers would perceive some communication skills to be more important than others. The tertiary purpose of this study was to characterize the social outcomes and communication characteristics of a young adult sample. Based on the results of other studies, we hypothesized that the majority of social outcomes would be poor and that performance on nonverbal communication skills would be poor and variable. The present study aims to provide preliminary information regarding which communication skills are imperative to assess and target during the transition period.

CHAPTER 4: METHODS

SURVEY DEVELOPMENT

To explore the specific communication needs of adolescents and adults with autism a survey was created for caregivers of the population. Best practice in determining the needs of a population includes surveying the key stakeholders of the population (Worall, 2002). We chose caregivers as participants because they play an integral role in the transition process for individuals with autism. The survey consisted of close-ended and open-ended questions with examples to guide the informants' responses. An extensive review of the literature related to the following topics was performed in order to develop survey questions:

- Outcome studies for individuals with autism (Billstedt et al., 2005; Eaves & Ho, 2008; Gillepsie-Lynch et al., 2012; Howlin et al., 2004; Taylor & Seltzer, 2010).
- Speech and communication deficits associated with adolescents and adults with autism spectrum disorder (Howlin et al., 2004, Mawhood et al., 2000; Schall & McDonough, 2006; Seltzer et al., 2003; Seltzer et al., 2007; Sigman & McGovern, 2005).
- Guidelines for functional communication assessment (Worrall et al., 2002).
- Guidelines for effective transition planning (Hendricks, 2009).

The survey included four parts. Part one consisted of basic information questions in order to verify that the participants meet the inclusion criteria. Part two contained questions pertaining to the caregiver's perception of their son/daughter's status, satisfaction and goals as they relate to the overlying outcome areas of living situation, quality of life, and employment. Part three included questions regarding respondents' son or daughter's communication status. Part four asked questions pertaining to communication skill abilities and how important the caregiver perceives these skills to be in order for their son or daughter to be successful.

PARTICIPANTS

The participants were recruited by contacting the directors of autism support agencies and autism organizations throughout the United States, as well as posting directly on the Yahoo groups discussion boards of autism organizations. It was requested that the directors email the survey information to members of their organization. Participants consented to take the survey by reading the initial page of the survey which included The University of Texas at Austin Institutional Review board approved text, and clicking "next" to begin the survey. They were informed that they could stop taking the survey at any time.

Between January 18th-March 15th, 94 participants started the survey on the study website. Of the 94 participants, 82 completed the survey. In order to be included in the study, participants needed to be the parent or caregiver of an individual with autism who

was between 14-31 years old and had a formal diagnosis of ASD. In addition, it was required that individuals be living within the United States. Because the survey was distributed through organizations and support groups, it was not guaranteed that people reading about the study would automatically meet the inclusionary criteria. A total of 10 survey responses were excluded because the individual's age did not fall within the specified range. Only 1 response was excluded due to lack of ASD diagnosis. An additional response was excluded because the respondent lived outside of the United States. Therefore, of the 82 completed surveys, 69 were included in the final data corpus. Responses were divided adolescent (age range= 14-21) and young adult cohorts (age range=22-31). We chose twenty-two years old as the cut off age for the young adult cohort because this is the age in which young adults age out of special education programs in the United States.

GLOBAL OUTCOME RATING

To determine the overall outcome rating of the young adult cohort we used a modified version of the criteria used in other outcome studies (Billstedt, 2005; Eaves & Ho, 2008; Gillepsie et al., 2012; Lord & Rutter, 1970). Utilizing these criteria allows for comparison to outcome data of other studies. Lower scores indicate better outcomes. Living independence ratings were 0=Lives independently or with friends in an apartment/house; 1= Lives with an assistant in an apartment/house; 2= Lives in a group home or residential facility; 3=Lives at home with family. Social life ratings were based on the extent of the individual's social network. Social life ratings were 0=spends time

with family, teachers, friends, and coworkers; 1= spends time with family members, teachers and friends; 2= spends time with family members and teachers; 3= spends time with family members. Employment ratings were 0= full-time paid position; 1=part-time paid position; 2=full-time volunteer position; 3=part-time volunteer position; 4= unemployed. Global outcome score was the sum of the three areas: 0-2= Very good outcome; 3-4=Good outcome; 5-7=Fair outcome; 8-10=Poor outcome; 11=Very poor outcome.

DATA ANALYSIS

We used SigmaPlot (Systat Software Inc., 2008) to perform statistical analysis procedures. Spearman rank order correlation was used to determine the relationship between level of verbal communication and communication skill performance and the relationship between level of verbal communication and parent/caregiver perception of communication skill importance. Significance was set at $p<.004$, corresponding to Bonferoni corrected $p<.04$ to correct for multiple comparisons (n=14 comparisons). To determine if differences existed between perceived importance of communication skills of individuals with different living situation and employment goals, individuals were sorted into groups. For living situation, the first group included individuals with a goal to live independently and the second group included individuals with a goal to live with some form of support. For employment, the first group included individuals with a goal to obtain a full-time paid job and the second group included individuals with a goal to obtain a part-time paid job, full-time volunteer position, part-time position or none of the

above. An ANOVA on ranks was performed. Significance for the ANOVA was set at $p<.05$. If a significant difference was found between goals, post-hoc pair-wise multiple comparisons were performed with Tukey Test, with $p<0.5$ as significant.

CHAPTER 5: RESULTS

To understand the transition period from educational experiences to functional life outcomes we investigated the communication needs of a sample of adolescents and young adults with autism through caregiver survey.

PARTICIPANT CHARACTERISTICS

DEMOGRAPHICS OF THE STUDY POPULATION

To interpret the main study results it is important to understand the nature of the respondents. The reported age of individuals with autism in this study ranged from 14-31 (mean=20;4), with 43 individuals in the adolescent cohort (age-14-21 years) and 26 individuals in the young adult cohort (age- 22-31 years). Individuals were reported to reside in states in all geographic regions of the United States, with the largest number of responses from the states of Texas (n=19) and Pennsylvania (n=17). The remainder of individuals resided in New Mexico (n=6), Massachusetts (n=5), Michigan (n=5), Nebraska (n=3), North Carolina (n=3), Wisconsin (n=2), Illinois (n=1), Alaska (n=1), Colorado (n=1), South Carolina (n=1), Maryland (n=1), Kentucky (n=1), Florida (n=1), and Virginia (n=1). The native language of all individuals was English with the exception of two responses.

CLINICAL DIAGNOSES

Respondents were asked to indicate what level of impairment the individual

exhibited. Twelve (17.6%) respondents reported a mild level of impairment, thirty-five (51.5%) a moderate level, and 21 (30.9%) a severe level. Respondents were also asked to list any other intellectual and/or medical impairment their son/daughter may have. We categorized concomitant disorders based on the axis of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV). Parent/caregiver responses indicated that of the 68 individuals with autism in this sample, twenty-six (38.2%) had a psychological disorder, two (2.9%) had a communication disorder, twenty-four (35.3%) had an intellectual disability, seventeen (25%) had a general medical or neurological condition, and five (7.4%) had a general medical condition. Information regarding concomitant disorders is summarized in Table 1.

COMMUNICATION CHARACTERISTICS

LEVEL OF LANGUAGE OUTPUT

To determine the level of language output of the individuals with autism, respondents were asked to indicate which of the following was most similar to how the individual communicates: "Verbal-uses lengthy sentences", "Verbal-primarily uses single words or phrases", "Alternative/Augmentative Communication (AAC) device", "Sign", "Nonverbal (uses gestures, eye gaze, etc.)" and "Other". It was determined that responses in the "Other" category met the criteria for one of the other categories and they were coded accordingly. Responses indicated that 30 (44.1%) individuals used lengthy sentences, 19 (28%) primarily used single words or phrases, and 10 (14.7%) used AAC

devices. Only 1 (.01) individual used sign and 8 (11.8%) were nonverbal, using gestures and eye gaze, etc. to communicate. See Figure 1 for a summary of the individuals' levels of language output.

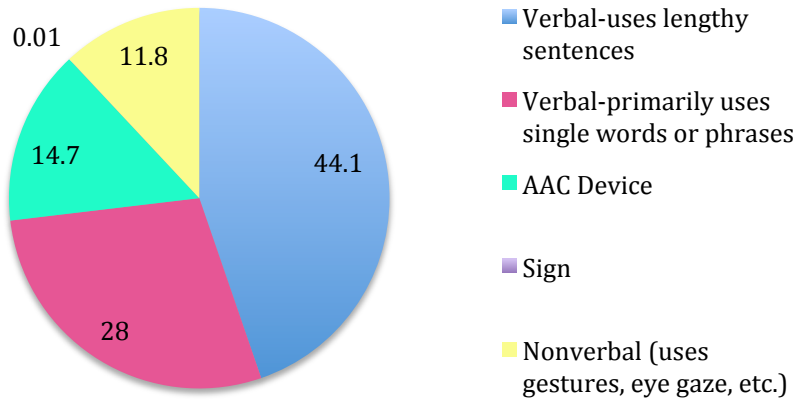
Table 1

Concomitant Disorders in the Population

Axis 1- Psychological Disorders	Axis 1- Communication Disorders	Axis 2- Intellectual Disability and Personality Disorders	Axis 3- General Medical Conditions, Neurological	Axis 3- General Medical Conditions, Other
ADHD (7) Anxiety Disorder (6) Depression (3) Mood Disorder-NOS (3) Bipolar Disorder (3) Obsessive Compulsive Disorder (3) Operational Defiant Disorder (1) Learning Disability-NOS (1) Reading disorder (1) Tourette's Syndrome (1)	Language disorder (1) Communication disorder- NOS (1)	Intellectual Disability (22) Fragile X (1)	Epilepsy (10) Cerebral Palsy (1) Fetal Alcohol Syndrome (1) Oral apraxia (1) Hypotonic (1) Normal Pressure Hydrocephalus (1) Arnold Chairi Malformation (1) Retinopathy of prematurity (1)	DiGeorge Syndrome (1) Hypothyroidism (1) Reactive Airway Disease (1) Crohn's Disease (1) Encopresis (1)

Figure 1

Level of language output



Percentages for each level of language output.

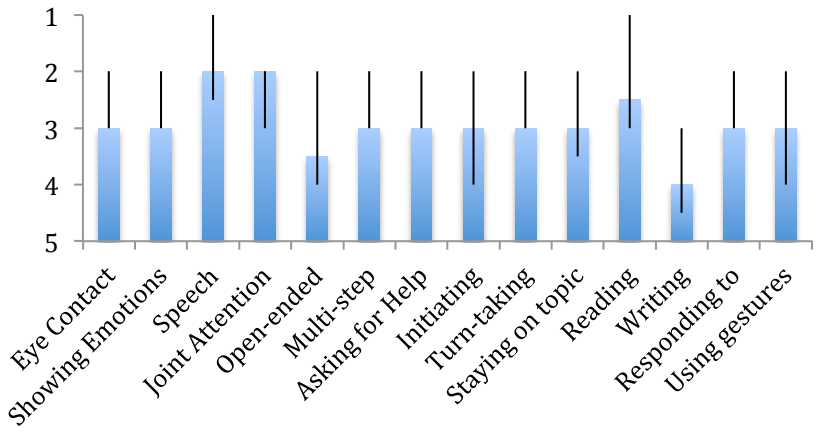
COMMUNICATION SKILL PERFORMANCE

To determine the communication characteristics of the individuals with autism, parents and caregivers were asked to rank the individual's ability to perform fourteen different communication skills: eye contact, showing emotions, speech, joint attention, answering open-ended questions, following multi-step instructions, asking for help, initiating conversations, following turn-taking rules, staying on topic, reading, writing, responding to nonverbal cues, and using gestures. Parents ranked the individual's ability to perform these skills on the same 5-point scale (1=Always, 2=Frequently, 3=Sometimes, 4=Occasionally, and 5= Never) for 11/14 skills. A 6th choice was added for the question pertaining to intelligible speech (6= My son/daughter does not speak).

The rating scale for "reading" and "writing" was 1=Excellent, 2=Very good, 3=Good, 4=Fair, and 5=Poor. The communication skill performance of the adolescent cohort is presented in Figure 2. The communication skill performance of the young adult cohort is presented in Figure 3.

Figure 2

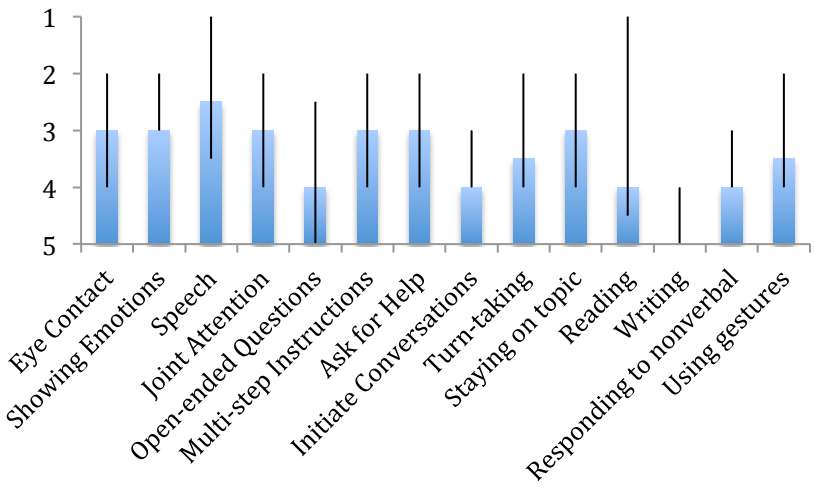
Communication Skill Performance of the Adolescent Cohort



Median values of the adolescent cohort (n=42) for each communication skill. Error bars: 25th-75th percentile. Scale represents 1 as highest ability level and 5 represents lowest ability level.

Figure 3

Communication Skill Performance of the Young Adult Cohort



Median values of the young adult cohort (n=26) for each communication skill. Error bars: 25th-75th percentile. Scale represents 1 as highest ability level and 5 represents lowest ability level.

Median values for the adolescent cohort were higher than those of the young adult cohort for "speech", "joint attention", "open-ended questions", "initiating conversations", "turn-taking", "reading", "writing", "responding to nonverbal cues and "using gestures". Median values were the same for both cohorts in "eye contact", "showing emotions", "following multi-step instructions", "asking for help" and "staying on topic."

RELATIONSHIP OF DEVELOPMENTAL LANGUAGE LEVEL TO COMMUNICATION SKILL PERFORMANCE

To further explore the communication characteristics of this sample, we examined the relationship between level of verbal communication and communication skill performance. Correlation data is summarized in Table 2.

Significant correlations existed for level of verbal output and "speech" ($p<.0000002$), "joint attention" ($p<.003$), "initiating conversations" ($p<.0000002$), "staying on topic" ($p<.00005$), "reading"($p<.00003$) and "writing" ($p<.0007$).

Table 2

Correlation between Level of Verbal Communication and Communication Skill Performance

Communication Skill	Correlation Coefficient	p value
Eye contact	.28	.02
Showing emotions	-.10	.43
Speech	.67	.0000002*
Joint attention	.36	.003*
Answer open-ended questions	.49	.00003
Follow multistep instructions	.06	.62
Asking for help	.02	.89
Initiating conversations	.65	.0000002*
Follow turn-taking rules	.10	.42
Staying on topic	.47	.00005*
Reading	.49	.00003*
Writing	.40	.0007*
Responding to nonverbal cues	-.02	.88
Using gestures	.27	.03

** indicates a significant correlation, nominal $p < 0.004$, corresponding to a Bonferonni corrected $p < 0.05$ for 14 comparisons.*

OUTCOMES

Respondents were asked to indicate the individual's current living situation, social life status, and employment status, their satisfaction level regarding these areas, and the individual's goals for the future in those areas.

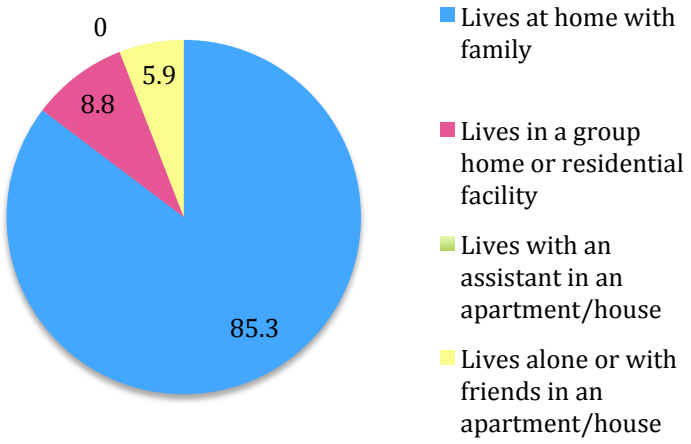
LIVING SITUATION

In terms of living situation, the majority (n=58, 85.3%) of the sample lived at home with family. The remaining individuals lived in a group home or residential facility (n=6, 8.8%) or by themselves or with friends in an apartment/house (n=4, 5.9%). Among the adult cohort, nineteen (73%) lived at home with family, four (26%) lived in a group home or residential facility, and three (11.5%) lived by themselves or with friends. Participants were asked to indicate their level of satisfaction towards their son/daughter's current living situation. Twenty-eight (41.2%) reported they were very satisfied, twenty (29.4%) were satisfied, nine (13.2%) were neutral, and eleven (16.2%) were dissatisfied. When considering satisfaction levels of the adult cohort (age=22-31) only, four (15.3%) respondents reported being very satisfied, eleven (42.3%) were satisfied, five (19.2%) were neutral, and six (23.1%) were dissatisfied. Regarding goals of the total sample for living situation, the most common goal was to live by themselves or with friends in an apartment/house for 27 (39.7%). The goal for 18 (26.5%) individuals was to live in a group home or residential facility, for ten (14.7%) it was to live with an assistant in an apartment/house and for thirteen (19.1%) it was to live at home with family. Data

regarding living situation is summarized in figures 4-8.

Figure 4

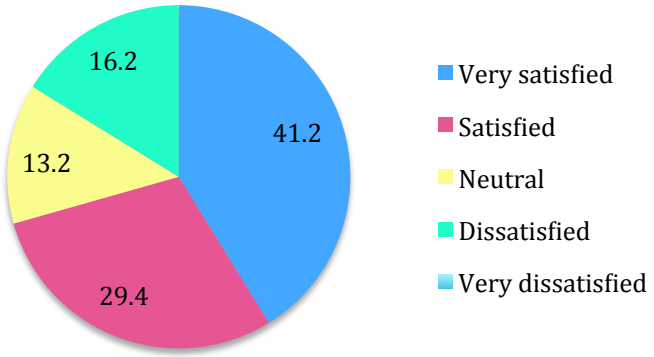
Living situation outcomes: Total Sample



Percentages of each living situation outcome.

Figure 5

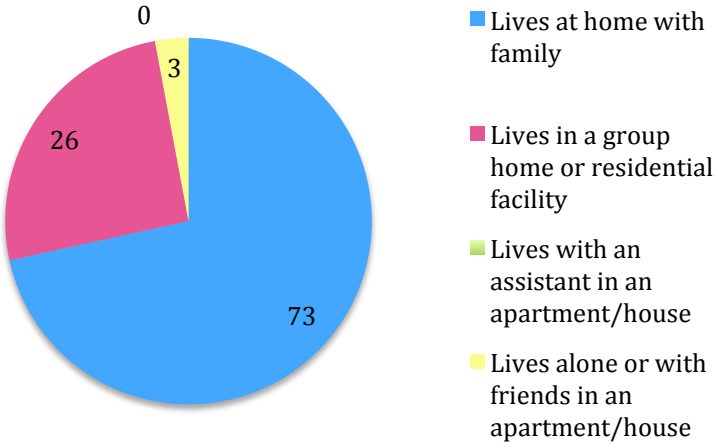
Satisfaction with living situation: Total sample



Percentages of each satisfaction level for current living situation.

Figure 6

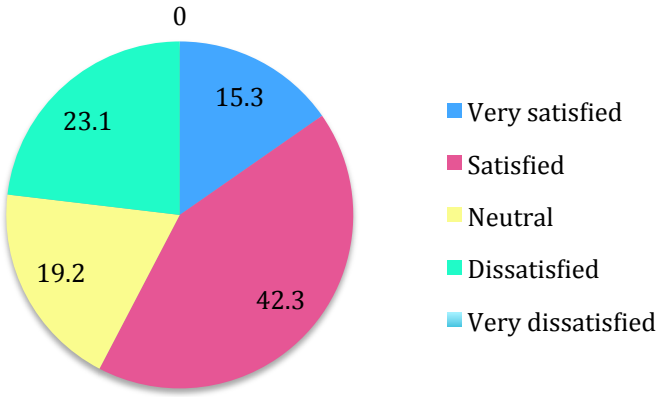
Living situation outcomes: Young Adult Cohort



Percentages of each living situation outcome.

Figure 7

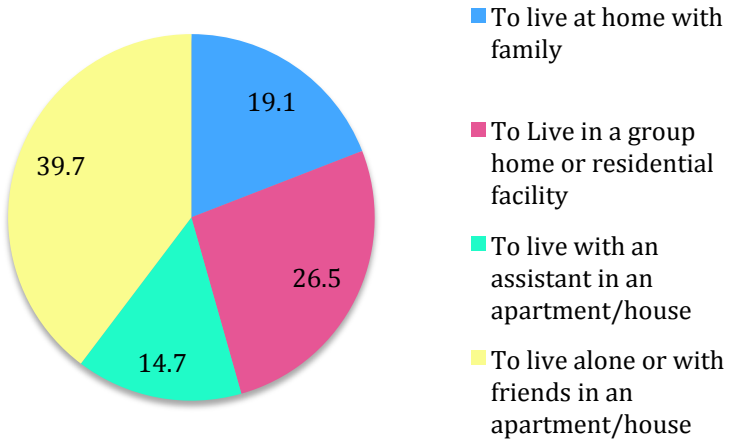
Satisfaction with living situation: Young adult sample



Percentages of each satisfaction level for current living situation.

Figure 8

Goals for living situation: Total sample



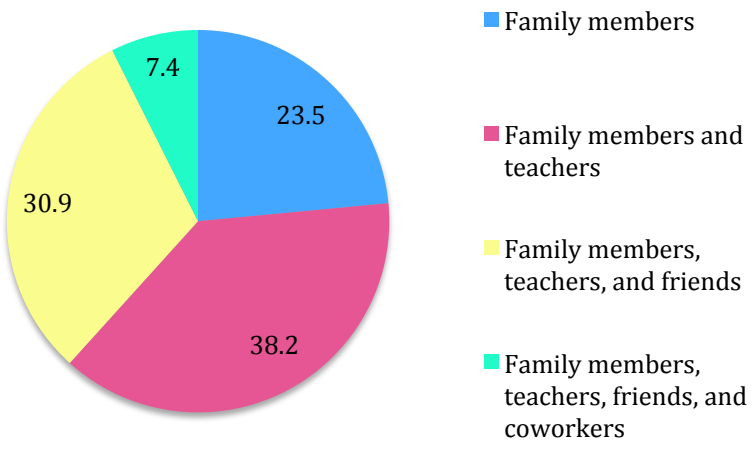
Percentages of each goal for living situation.

SOCIAL LIFE

When asked about the social network of the individuals with autism, respondents reported that sixteen (23.5%) only spent time with their family, twenty-six (38.2%) spent time with their family and teachers, twenty-one (30.9%) spent time with their family, teachers, and friends (30.9%) and five (7.4%) spent time with their family, teachers, friends and coworkers. Among the adult cohort, eleven (42.3%) only spent time with family, six (23.1%) spent time with family and teachers, six (23.1%) spent time with family, teachers, and friends and three (11.5%) spent time with family, teachers, friends, and coworkers. In terms of satisfaction level, one (1.5%) respondent reported being very satisfied, twelve (17.6%) were satisfied, nineteen (27.9%) were neutral, twenty-nine (42.6%) were dissatisfied and seven (10.3%) were very dissatisfied. Within the young adult cohort, four (15.4%) respondents indicated they were satisfied, seven (27%) were neutral, ten (38.5%) were dissatisfied, and five (19.2%) were very dissatisfied. Regarding goals in the area of the social life for the total sample, six (8.8%) indicated their goal was to spend more time with family, for thirteen (19.1%) it was to spend more time with friends, for twenty-seven (39.7%) it was to make more friends, and for twenty two (32.4%) it was to get involved in more activities. Data regarding social life is summarized in figures 9-13.

Figure 9

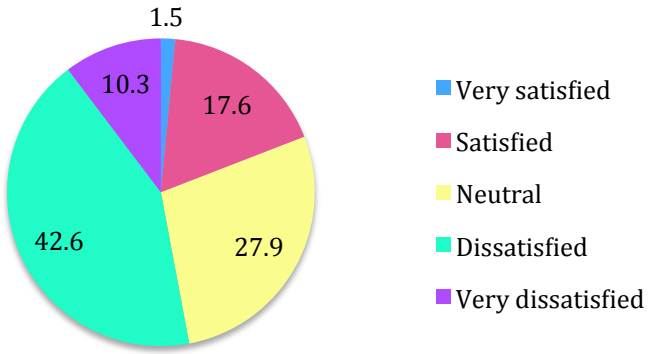
Social life outcomes: Total sample



Percentages for each social life outcome.

Figure 10

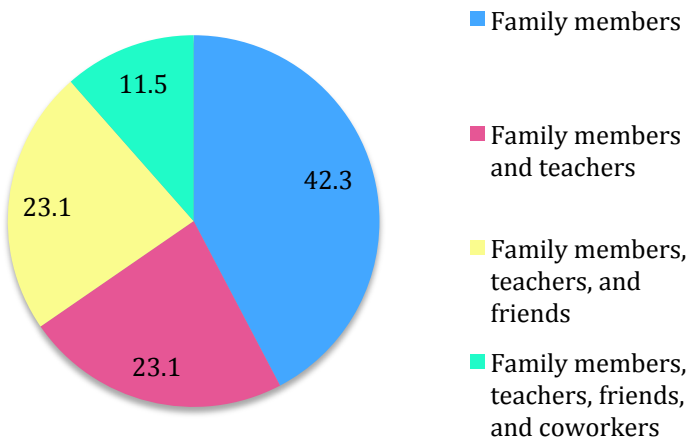
Satisfaction with social life: Total sample



Percentages for each satisfaction level for social life.

Figure 11

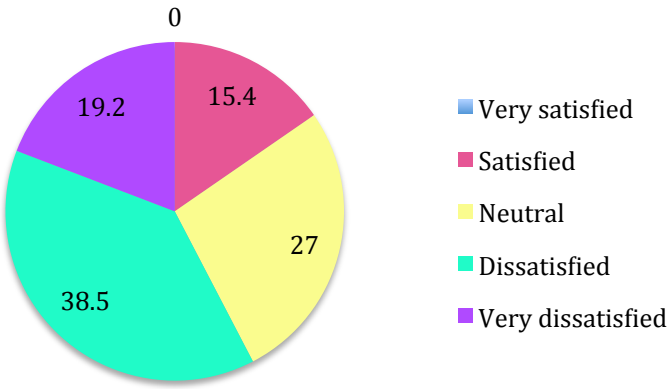
Social life outcomes: Young adult sample



Percentages for each social life outcome.

Figure 12

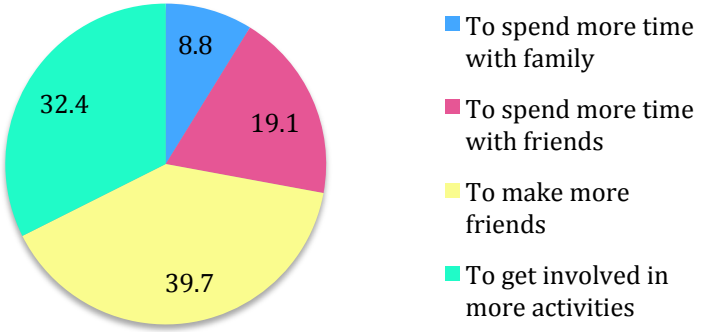
Satisfaction with social life: Young adult sample



Percentages for each level of satisfaction for social life.

Figure 13

Social life goals: Total sample



Percentages for each social life goal.

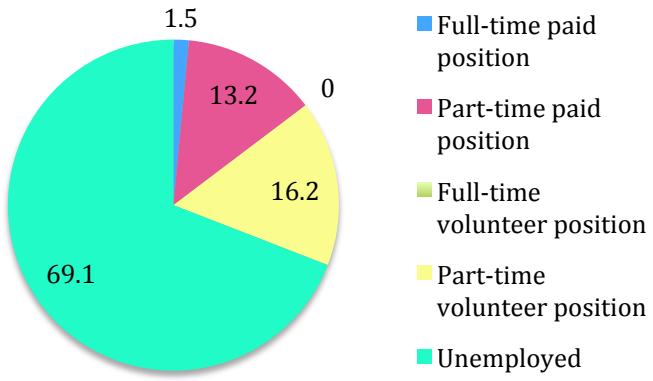
EMPLOYMENT

When asked if individuals had a job, forty-seven (69.1%) individuals were reported to be unemployed, eleven (16.2%) had a part-time volunteer position, nine (13.2%) had a part-time paid position, and only one (1.5%) had a full-time paid position. Among the adult cohort (n=26), fifteen (57.7%) were unemployed, seven (27%) had a part-time paid job, three (11.5%) had a full-time volunteer job, and one (3.8%) had a full-time paid job. When asked about satisfaction level, four (5.9%) indicated they were very satisfied, ten (14.7%) were satisfied, twenty-four (35.3%) were neutral, seventeen (25.0%) were dissatisfied, and thirteen (19.1%) were very dissatisfied. When considering the adult cohort only, two (7.7%) respondents indicated being very satisfied, four (15.4%) were satisfied, four (15.4%) were neutral, six (23.1%) were dissatisfied, and ten (38.5%)

were very dissatisfied. In terms of goals for the total sample, twenty-six (38.2%) indicated their goal was a full-time paid position, twenty-five (36.8%) a part-time paid position, two (2.9%) a full-time volunteer position, six (8.8%), and nine (13.2%) indicated they did not have a future goal in the area of employment. Data regarding employment is summarized in figures 14-18.

Figure 14

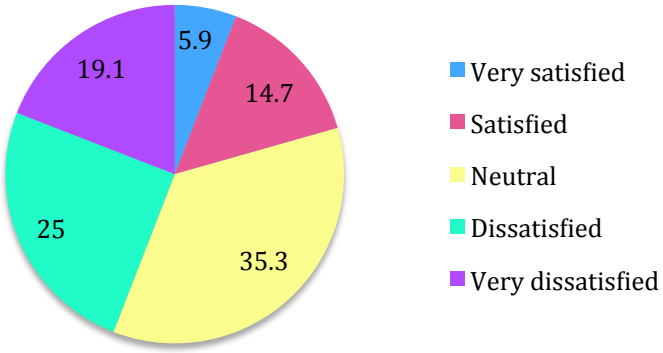
Employment outcomes: Total sample



Percentages for each employment outcome.

Figure 15

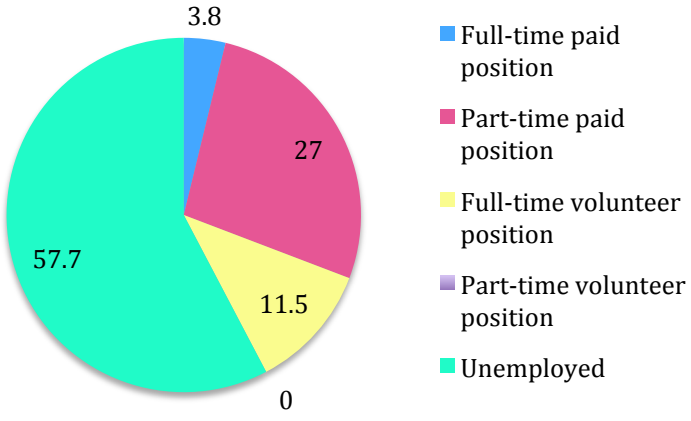
Satisfaction with employment: Total sample



Percentages for each satisfaction level for employment.

Figure 16

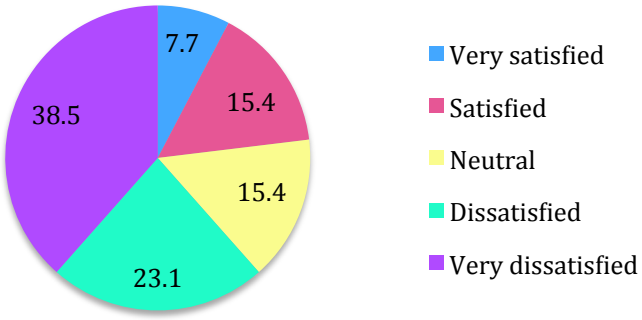
Employment Outcomes: Young adult sample



Percentages for each employment outcome.

Figure 17

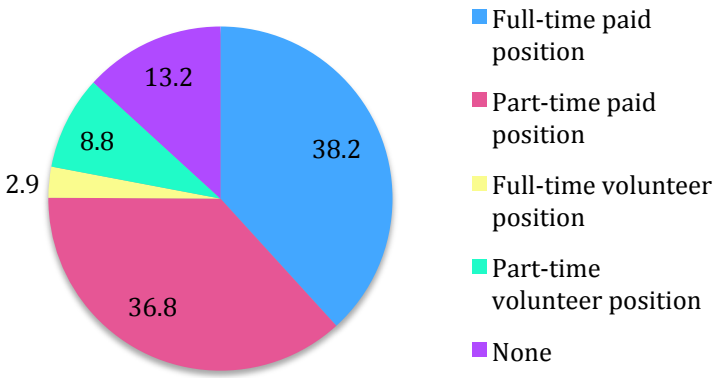
Satisfaction with Employment: Young Adult Sample



Percentages for each satisfaction level for employment.

Figure 18

Employment goals: Total sample



Percentages for each employment goal.

GLOBAL OUTCOME SCORES

When considering the overall outcome of the individuals in the young adult cohort, two individuals (7%) achieved a good outcome, eleven (42%) achieved a fair outcome, and thirteen (50%) achieved a poor outcome. See Table 3 for a summary of the outcome results.

Table 3

Global Outcome Scores of the Young Adult Cohort

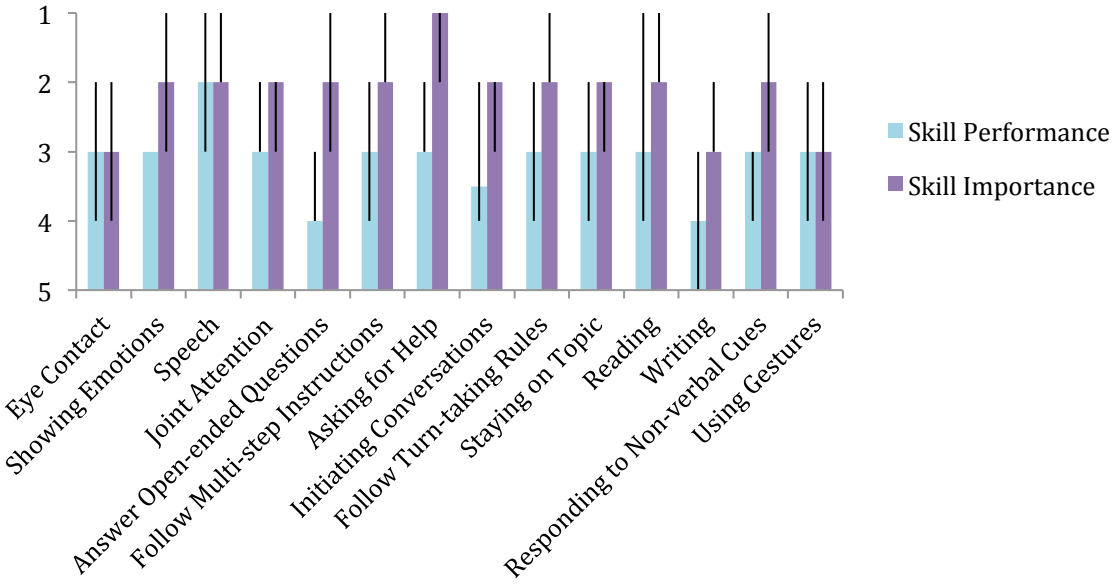
GOS	Very good	Good	Fair	Poor	Very Poor
n (%)	0	2 (7%)	11 (42%)	13 (50%)	0

PARENT/CAREGIVER PERSPECTIVE REGARDING COMMUNICATION SKILLS

Parents and caregivers were asked to rate the importance of the communication skills on a 5-point scale (1=essential, 2=very important, 3=moderately important, 4=slightly important, and 5=not important at all). See Figure 4 for a summary of the data analyzed regarding communication skill performance and parent/caregiver perspective. The greatest disparities between median values for communication skill performance and importance of communication skills were for "asking for help" (d=2), "answering open-ended questions" (d=2), and "initiating conversations" (d=1.5).

Figure 19

Communication Skill Performance and Perceived Importance



Median values for each communication skill and perceived importance level of each skill. Error bars: 25th-75th percentile. Scale represents 1 as highest ability level/importance level and 5 represents lowest ability level/lowest important level.

RELATIONSHIP OF VERBAL ABILITY AND CAREGIVER PERCEPTION OF COMMUNICATION SKILL VALUE

To determine if there was a relationship between verbal ability and caregiver perception of communication skill value, ANOVA on rank was performed. Significant correlations existed for the level of verbal output and the perceived importance of "initiating conversations" ($p<.0006$), "reading" ($p<.002$) and "responding to nonverbal

cues" (p<.0005). A strong trend towards significance existed for level of verbal output and the perceived importance of "speech" (p<.005), "staying on topic" (p<.005), and "writing" (p<.007). Data related to this question is summarized in Table 4.

Table 4

Correlation between Level of Verbal Communication and Communication Skill Importance

Communication Skill	Correlation Coefficient	p value
Eye contact	.19	.13
Showing emotions	.13	.31
Speech	.34	.005^
Joint attention	.24	.04
Answer open-ended questions	.29	.02
Follow multistep instructions	.23	.06
Asking for help	.16	.20
Initiating conversations	.41	.0006*
Follow turn-taking rules	.27	.03
Staying on topic	.34	.005^
Reading	.38	.002*
Writing	.32	.007^
Responding to nonverbal cues	.41	.0005*
Using gestures	.004	.98

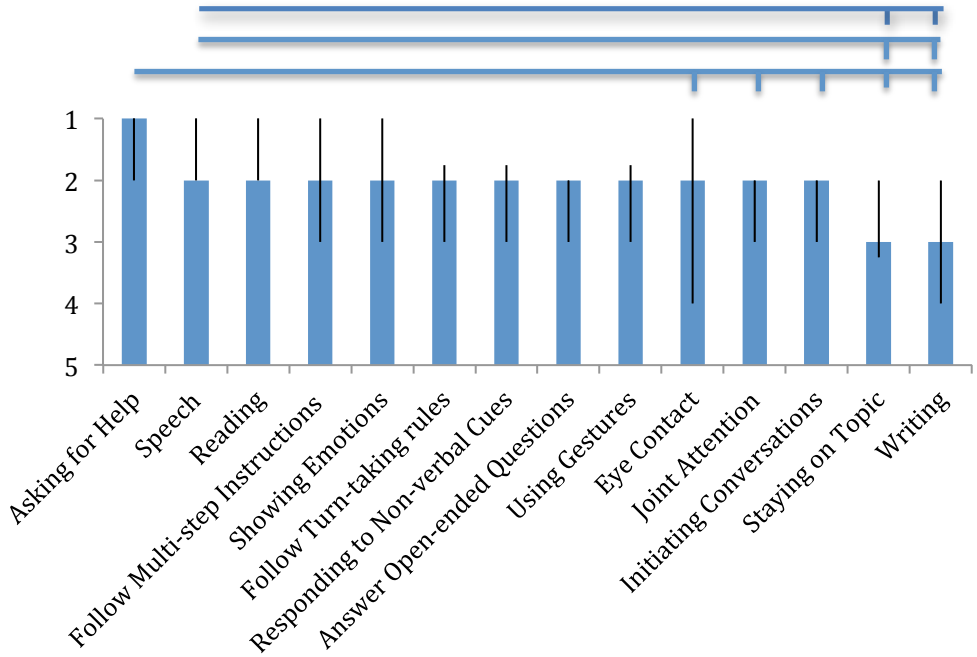
** indicates a significant correlation, nominal p < 0.004, corresponding to a Bonferonni corrected p < 0.05 for 14 comparisons. ^ indicates strong trend toward significance*

RELATIONSHIP OF FUNCTIONAL LIVING GOALS AND PARENT/CAREGIVER PERCEPTION OF COMMUNICATION SKILL IMPORTANCE

The ANOVA demonstrated that there were significant differences between the perceived importance of communication skills for living goals 1-3 ($p<.001$). Living goals 1-3 were "to live at home with family", "living in a group home or residential facility", and "living with an assistant in an apartment or home". Post-hoc multiple comparisons showed that asking for help was perceived as more important than writing, staying on topic, initiating conversations, eye contact, and using gestures. Speech was perceived as more important than writing and staying on topic. Reading was perceived as more important than writing and staying on topic. A summary of the data regarding the importance of skills for living goals 1-3 is presented in Figure 20.

Figure 20

Living Goals 1-3: Important Skills



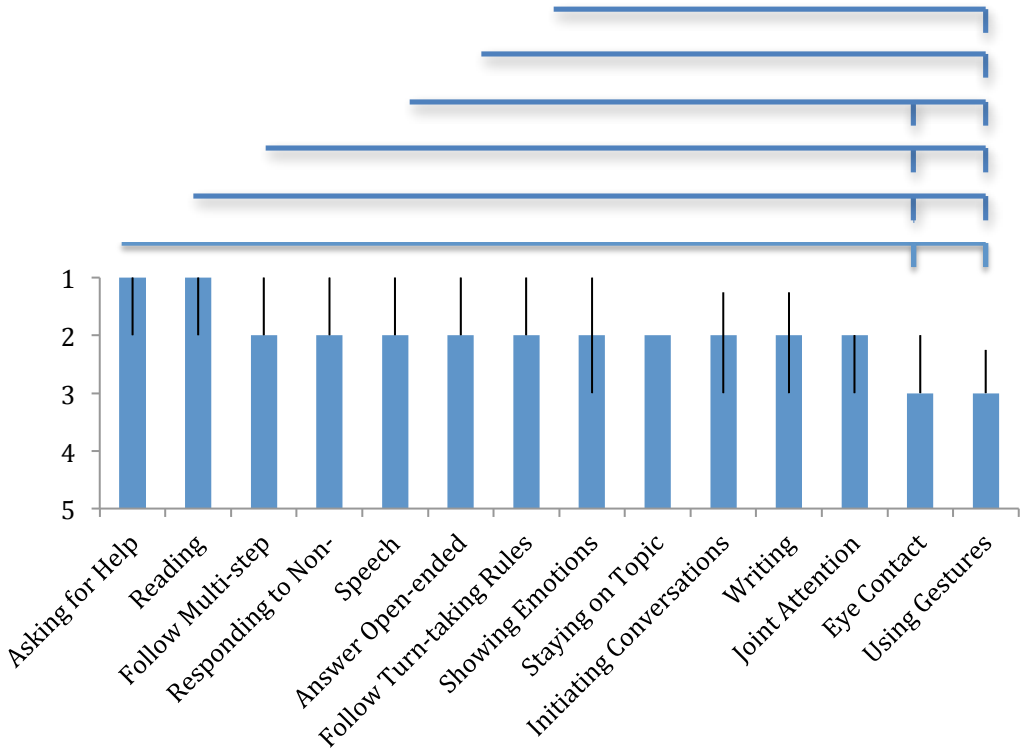
Skills presented from left to right as most important to least important as ordered by ANOVA on ranks. Error bars represent the 25-75% range. Bars indicate significant differences as determined by post-hoc multiple comparison tests ($p<.05$).

The ANOVA demonstrated that there were significant differences between the perceived importance of communication skills for living goal 4 ($p<.001$). Living goal 4 was to "live by themselves or with friends in an apartment/house." Post-hoc multiple comparisons showed that asking for help, reading, following multi-step instructions, responding to nonverbal cues, and speech were perceived as more important than eye contact and using gestures. Open-ended questions and turn-taking rules were perceived

to be more important than using gestures. A summary of the data regarding the importance of skills for living goal 4 is presented in Figure 21.

Figure 21

Living goal 4, Important skills



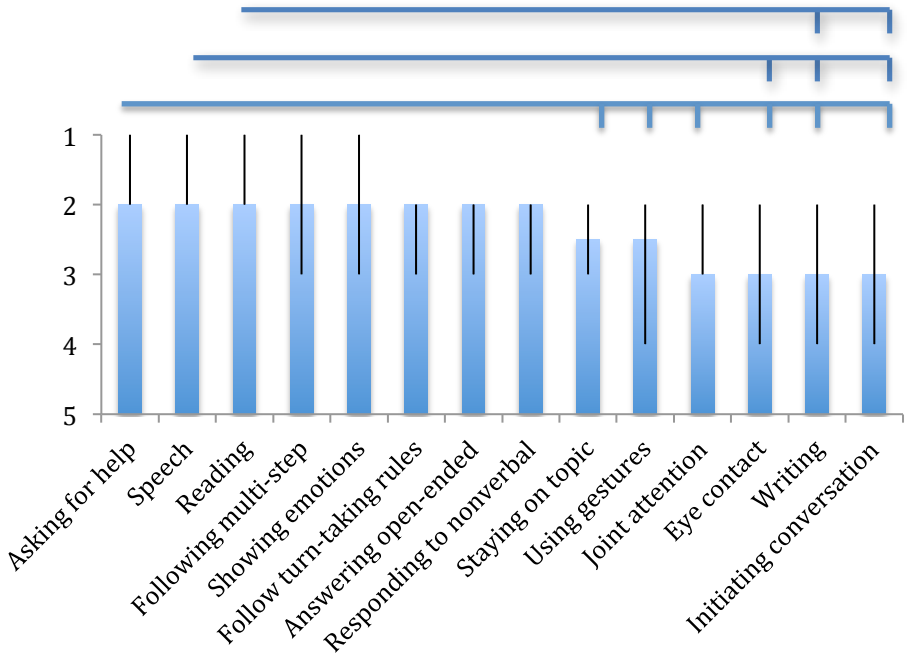
Skills presented from left to right as most important to least important as ordered by ANOVA on ranks. Error bars represent the 25-75% range. Bars indicate significant differences as determined by post-hoc multiple comparison tests ($p<.05$).

The ANOVA demonstrated that there were significant differences between the perceived importance of communication skills for job goals 2-4 ($p<.001$). Job goals 2-4 were "part

time paid position", "full-time volunteer position" and "part-time paid position." Post-hoc multiple comparison showed that asking for help was perceived as more important than initiating conversations, writing, eye contact, using gestures, joint attention and staying on topic. Speech was perceived as more important than initiating conversations, writing, and eye contact. Reading was perceived as more important than initiating conversations and writing. A summary of the data regarding the importance of skills for job goals 2-4 is presented in Figure 22.

Figure 22

Job Goals 2-4, Important Skills



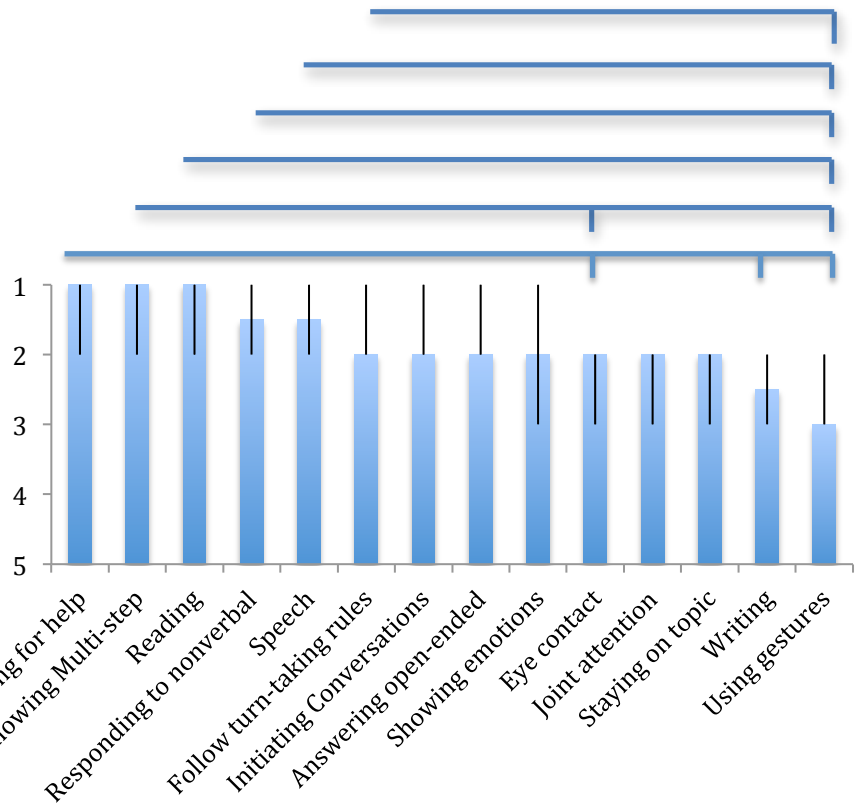
Skills presented from left to right as most important to least important as ordered by ANOVA on ranks. Error bars represent the 25-75% range. Bars indicate significant differences as determined by post-hoc multiple comparison tests ($p<.05$).

The ANOVA demonstrated that there were significant differences between the perceived importance of communication skills for job goal 1 ($p<.001$). Job goal 1 was a "full time paid position". Post-hoc multiple comparisons showed that asking for help was perceived as more important than using gestures, eye contact and writing. Following multi-step instructions was perceived as more important than using gestures and eye

contact. Reading, responding to nonverbal cues, speech and following turn-taking rules were all perceived to be more important than using gestures. A summary of the data regarding the importance of skills for job goal 1 is presented in Figure 23.

Figure 23

Job Goal 1, Important Skills



Skills presented from left to right as most important to least important as ordered by ANOVA on ranks. Error bars represent the 25-75% range. Bars indicate significant differences as determined by post-hoc multiple comparison tests ($p<.05$).

ANSWERS TO OPEN-ENDED QUESTIONS

Due to the exploratory nature of this study, we were interested in obtaining more in-depth information regarding communication needs. We coded responses that provided specific information.

EYE CONTACT

Thirty-four participants provided specific information regarding eye contact. We coded responses for three central themes: *expectations of others* (n=15), *not necessary* (n=9), *helpful for the individual* (n=10). For example, a respondent from the *expectations of others* category wrote, "People who don't understand autism think lack of eye contact means the person is uninterested/disrespectful and that is not the case. This could hold him back in employment situations." A respondent from the *not important* group wrote, "eye contact is not important with the job because the workplace includes people from other cultures that are okay with no eye contact." There were two other individuals in this group that also indicated that eye contact would not be necessary for their aspiring job. From the *helpful for the individual group*, a respondent wrote, "it helps them to see facial expressions and to hopefully begin to recognize differences in emotion."

SHOWING EMOTIONS

Twenty-six respondents provided specific information regarding the importance of "showing emotions". The majority expressed that *displaying frustration in an appropriate and safe manner* (n=16) would be important in an employment or social

situation. For example, one respondent stated, "Keeping frustrations in when she is employed will help her better deal with the real world." Others felt that if their son/daughter expressed emotions appropriately, *people would be able to assist him/her* (n=3). One respondent wrote, "It would help others understand his level of anxiety and be able to assist him when needed." Finally, several respondents believe improvement with this skill would *help him/her to make friends* (n=7). For example, "It would help in relationships. But I think he has difficulty understanding emotion, so the emotions he shows may be inappropriate."

SPEECH

Thirteen respondents provided specific information regarding how speech skills would help their son/daughter achieve their goals. Five respondents provided answers related to: *Speech is more efficient and what society expects* (n=5). For example, "I think it may be more important on a job because that is what society seems to expect while family and friends are often more relaxed with different ways of communicating." On the other hand, only one individual indicated that *society's perspective regarding AAC needs to change*. Others specifically mentioned *articulation issues* (n=5) as something that is impeding their son/daughter from achieving their goals. For example, one respondent wrote, "he has great salesman skills but articulation may make him not get a job in that area." Two respondents believed that good speech skills would *reduce problem behaviors*.

JOINT ATTENTION

Six respondents provided specific information regarding "showing attention". Three respondents believed *showing awareness and interest of things other people find interesting* would help their son/daughter to be successful. Three respondents stated that sharing attention would help their son/daughter *to make friends.*

ANSWERING OPEN-ENDED QUESTIONS

Twelve people provided specific information regarding answering open-ended questions. Three responses indicated that this skill would be *important for his/her job.* For example, one respondent indicated, "My son wants to educate people on "disabilities." It will be very important for him to be able to answer open-ended questions in order for him to do his work." Other responses were variable. One respondent exclaimed, "*Answering any question would be great*!!!" Another wrote that this skill would be *important in a medical situation*. One respondent indicated that *working on comprehending questions* would be helpful. Another respondent stated that *working on reducing pauses* when responding would help improve the natural flow of communication with peers. One respondent stated that *teaching this skill through writing/typing* would be better than through pictures. Another believed that this skill is *not important for work* because their son is a quantitative researcher that does "close-ended work." One respondent mentioned that their son knows that he is expected to do this but *does not remember to in formal situations*. They stated that, "He would benefit

from practice in doing this-having to listen to someone else while he holds his own thoughts…"

FOLLOWING MULTI-STEP INSTRUCTIONS

Ten respondents indicated that following multistep directions would help their son/daughter become more independent in all areas. For example, one respondent indicated, "ability to do multistep instructions would probably allow for gradual fading/fazing out of job coach etc., more leeway for individual work." Two respondents mentioned that *developing a strategy for remembering steps* would be helpful, including *visual scheduling*, *using a phone calendar* and *note-taking*. Another respondent indicated that *demonstrating initiative with tasks that do not have a direct benefit* would help with chores at home.

ASKING FOR HELP

Five respondents indicated that asking for help is important regarding *safety issues*. For example, one respondent wrote, "could prevent them from being hurt of injured or others from being hurt or injured or prevent property damage etc. Four respondents reported that asking for help would assist their son/daughter in *getting their needs met*. Three respondents suggested, that their son/daughter *needs to learn that asking for help is okay.* For example, one respondent wrote, "He feels that if he asks for help he's not capable of doing the task. Will often say I know how to do that, even if he has never done it before…He needs to learn that asking for help is a way to learn

something new- not a sign of "ignorance."" Two respondents wrote that asking for help would help their son or daughter to *gain new knowledge.* Two others wrote that if their son/daughter had learned to ask for help earlier on in their lives, their *other issues might be much smaller*. Two respondents felt that with increased ability to ask for help, their son/daughter would experience *less frustration and anxiety*. One respondent mentioned that asking for help would help their son to *advocate for himself*. Another stated that they wish their son would be able to *ask other people besides his parents for help*. Finally, one respondent mentioned that asking for help would *decrease dependence on commands and instructions*.

INITIATING CONVERSATIONS

Seven respondents indicated that improvement in initiating conversations would help their son/daughter to *make friends* and two reported that it would help their son/daughter *get along at work*. Other responses were related to: *larger impact in chosen field of education, having a girlfriend, would help others to get to know him better,* and *help him learn and grown from others.* One respondent wrote, "He says, 'Talking people say the least.' He is by nature a quiet person who believes in listening, as many other nondisabled individuals are."

TURN-TAKING

Five respondents indicated that turn-taking skills would benefit their son/daughter in employment situations because turn-taking *demonstrates politeness and discipline*.

For example, one respondent stated, "It shows discipline which carries over into employability and making friends".

STAYING ON TOPIC

Six respondents reported that their son/daughter *doesn't talk enough to stay on topic*. One of these respondents noted, "…a higher priority would be for him to just communicate more, in general, even if he doesn't stay on topic." Two respondents indicated that staying on topic would *increase their son/daughter's ability to focus.* One respondent suggested that people who stay on topic are *easier to live and work with*. Another respondent wrote that staying on topic *would help others to have more interest in what their son is saying*. In contrast, one respondent wrote, "*This isn't too big a deal* I know lots of people who can't stay on topic…"

READING

Two respondents indicated that functional reading such as *following recipes and reading bus schedules* would be important for daily life. Two others reported that *reading signs would help prevent safety issues.* Two respondents indicated that *following written instructions would help at work* and two others specifically mentioned that *reading job applications and contracts* would be helpful.

WRITING

Three respondents indicated that being able to *sign your signature* would be

helpful in work situations. Five respondents reported that writing needs down would be helpful in situations in which others cannot understand the spoken request. For example, one respondent wrote, "…writing skills are more practical in some situations. You can't always be a keyboard. He could write his needs down." One respondent indicated that being able to *fill out applications*, and *make lists* and *checklists* would help their child succeed. Nine respondents reported that their son/daughter uses *typing or texting* instead of writing to communicate and improvement with this skill would be important for their son/daughter's success.

RESPONDING TO NONVERBAL COMMUNICATION

In terms of nonverbal communication, three respondents mentioned that improvement with nonverbal cues would help their son/daughter *get along with other in a work environment*. Two respondents mentioned it would be especially important for their son/daughter to *recognize anger* to avoid misunderstandings. Two respondents reported that responding appropriately to nonverbal cues would help their son/daughter *to make friends* and one indicated that improvement with this skill would *reduce bullying and teasing directed at their son/daughter*. One respondent reported that this skill is *especially important regarding romantic relationships.*

USING GESTURES

Responses regarding the importance of using gestures were variable. One respondent indicated that using gestures more often would help others' recognize their

son's wants and needs. Another respondent indicated that this skill would be beneficial to learn for public speaking. One respondent mentioned that being able to use gestures appropriately is important for situations in which AAC is not accessible. One respondent stated, "Being able to indicate 'yes' and 'no' accurately would be life changing." In contrast, one respondent reported that using gestures is not essential "in this exciting new virtual world."

OTHER COMMUNICATION SKILLS

Respondents were asked to list other communication skills they felt were essential for the individual with autism's success. Communication skills listed by more than one participant which were determined to be different or more specific than the fourteen communication skills of the survey included: listening comprehension (n=3), using IPAD or other communication device more independently (n=3), and using social media appropriately (n=2). Other communication skills listed by one participant each included: "hard time talking about himself", "requesting one thing at a time instead of many", "pragmatics of language (metaphor especially)", "learning to speak in longer phrases", "reading comprehension", "independent keyboard skills," "spelling in sign", "getting severe problem behavior down", "negative tone", "communicating pain and fear", "understanding humour", "making independent choices", and "expressing appreciation independently."

CHAPTER 6: DISCUSSION

The primary purpose of the present study was to explore the specific communication needs of individuals with autism who are transitioning out of secondary education from the perspective of their parents and caregivers. The secondary purpose was to determine if certain social goals of the individual with autism predicted which communication skills parents and caregivers perceived as important. Finally, the tertiary purpose was to characterize the communication characteristics and social outcomes of a young adult sample.

COMMUNICATION CHARACTERISTICS AND OUTCOMES OF THE SAMPLE

First, we examined the level of language output of the individuals with autism. Approximately 72% of our sample used verbal speech as their primary form of communication, which is consistent with studies that have demonstrated that approximately 60-70% of individuals with autism develop some level of functional speech by adulthood (Mawhood et al., 2000; Seltzer et al., 2003).

Next, we looked separately at the communication skill performance of the adolescent and young adult samples. Interestingly, the median values were higher for the adolescent group for nine skills: speech, joint attention, open-ended questions, initiating conversations, turn-taking, reading, writing, responding to nonverbal cues and using gestures. Median values were the same for both groups for five skills: eye contact,

showing emotions, following multi-step directions, staying on topic, and asking for help. Seltzer and colleagues (2003) found that an adolescent sample (n=251) outperformed an adult sample (n=154) on nonverbal communication skills; however, the adult sample outperformed the adolescent sample on verbal communication skills. In the present study, the adolescent cohort outperformed the adult cohort on a combination of verbal and nonverbal communication skills and the adult sample did not outperform the adolescent sample on any skills. Increased access to early childhood services could explain the differences in scores for the adolescent and young adult cohorts.

Next, we examined if individuals' level of verbal output predicted their communication skill performance. Not surprisingly, level of verbal output was significantly correlated with speech, joint attention, staying on topic, initiating conversations, reading and writing. This result indicates that in this sample, an adolescent or young adult with autism who primarily uses verbal means of communication does not necessarily perform the following skills better than an adolescent or young adult with autism who uses primarily nonverbal means to communicate: eye contact, showing emotions, asking for help, following multistep instructions, following turn-taking rules, responding to nonverbal cues, and using gestures.

Finally, we explored the outcomes of the young adult sample. Overall, outcomes were poor with only two individuals achieving a good outcome, eleven achieving a fair outcome and thirteen achieving a poor outcome. These outcomes are similar to those

found by the majority of outcome studies conducted in the past 10 years (Billstedt et al., 2005; Howlin et al., 2004; Taylor & Seltzer, 2010). Several recent studies have demonstrated slightly better outcomes (Eaves & Ho, 2008, Gillepsie-Lynch et al., 2012). Our outcomes results may have been worse when compared to these recent studies because our cohort included reports on a higher number of lower functioning individuals. Of the forty-eight individuals studied by Eaves and Ho (2008), 39% had not been formally diagnosed with an autism spectrum disorder. Gillepsie-Lynch and colleagues (2012) reported that their sample of twenty individuals had on average a higher developmental quotient and language abilities than the participants in their original sample. Our results may have also been different because of the participant recruitment method. It might be more likely that individuals seeking support through autism organizations have a son/daughter who has not achieved hoped for social goals.

In summary, caregiver perceptions of outcomes for the young adults in our sample were poor. Additionally, the communication skills performance of these individuals was poor and variable. This result indicates that there is a need to improve specific communication skills for this population of lower functioning individuals based on caregiver perceptions.

PARENT/CAREGIVER PERCEPTION OF COMMUNICATION SKILL IMPORTANCE

Regarding importance of communication skills, median values revealed that

parents and caregivers perceived asking for help to be an essential skill for their son/daughter's success. Skills which were perceived to be important included: showing emotions, joint attention, speech, answering open-ended questions, initiating conversations, staying on topic, following multi-step directions, following turn-taking rules and reading. Eye contact, using gestures and writing were perceived to be only moderately important. When comparing the communication skill performance of the sample and the perceived importance of these skills, the largest disparities existed for asking for help, answering open-ended questions, and initiating conversations. This finding suggests that these skills may be especially important to target.

We also examined the relationship between the individuals' level of language output and parent/caregiver perception of communication skill importance. Level of verbal output was significant correlated with perceived importance of initiating conversations, reading and responding to nonverbal cues. There was a strong trend toward significance for speech and joint attention. This finding demonstrates that it is important to consider the individual's mode of communication when formulating functional communication treatment goals.

Parents were also asked if there were any additional communication skills they felt were essential for their son/daughter's success. Communication skills, which were mentioned more than once, included: listening comprehension, using an IPAD or other communication device more independently, and using social media appropriately.

RELATIONSHIP OF FUNCTIONAL LIVING GOALS AND PARENT/CAREGIVER PERCEPTION OF COMMUNICATION SKILL IMPORTANCE

Finally, we examined the relationship of reported goals in the areas of living situation and employment and parent/caregiver's perception of communication skills performance. Groups were separated according to the living and employment goals of the individual with autism. Results demonstrated that certain skills were rated as more important than other skills within each group. Across groups, asking for help was uniformly rated as more important than other skills. All other skills were rated differently across groups reflecting that the importance of communication skills varies depending on the living situation and employment goals of the individuals.

Within the open-ended responses, parents provided information for how improvement with these communication skills would help their son/daughter achieve important goals in the areas of living situation, social life and employment. Participants reported that they did not find certain communication skills, which are typically focused on in intervention approaches for individuals with ASD, essential for their son/daughter's success. For example, a surprisingly large number of respondents indicated that they did not believe eye contact is important. Although this is a skill that is targeted in early childhood intervention approaches, these results suggest that there may be more important skills to focus on in adolescence from caregiver's perspectives.

Interestingly, for several communication skills, responses could be divided into a group in which the parents believed improvement with the skill would help their son/daughter meet the expectations of others and another group in which parents felt that improvement with the skill would be helpful for their son/daughter themselves. A few responses mentioned that our society should be better informed about the characteristics of autism. These responses reflect the perspective of the Neurodiversity movement, which advocates that neurological disorders should be considered a natural difference. Some members of this movement believe that its principles should only apply to higher functioning individuals (Jaarsma & Welin, 2012). Regardless, it seems it would be important for functional communication skills to be addressed, but also for society to be educated about the core communication characteristics of individuals with autism.

LIMITATIONS

There are several limitations to the present study. First, the results from the present study should be interpreted with caution due to the small size of the sample. Second, a convenience sampling procedure was used. The survey was distributed through autism organizations and support groups. It may be more likely that individuals seeking support through these organizations have a son/daughter who has not achieved desired social goals. Also, communication skill performance was determined based on a 5-point scale. Future research in this area should utilize measures that are more sensitive to determine skill level.

CLINICAL IMPLICATIONS

Current transition planning guidelines recommend the transition team administer cognitive, adaptive behavior, and vocational assessments (Sitlington & Clark, 2007). Based on the nature of the communication deficits that result from autism and the results of this survey, we suggest that communication assessment be included in transition assessment for individuals with autism. Communication skills included on the Transition Planning Inventory-Revised (Clark & Patton, 2009) include speaking, listening, reading and writing. Although these skills are perceived to be important, results from this survey indicate that performance on these skills does not appear to predict performance on a variety of other communication skills for individuals with autism. Therefore, it would be essential to assess all skills that are known to persist through adulthood in addition to speaking, listening, reading and writing.

Additionally, the survey results suggest that there may be communication skills that are especially important to target. Speech-language pathologists should consider that, overall, parents and caregivers perceived certain communication skills to be more important than others. The perceived importance of communication skills differed depending on the social goals of the individuals; therefore, an individual's larger goals should be considered when developing treatment goals. Using questions from this survey could assist speech-language pathologists in identifying specific areas of communication

to target in intervention.

CONCLUSION

The present study adds to the current body of literature pertaining to transition aged youth with autism by suggesting specific communication skills that are important to assess during transitional planning. These findings highlight the importance of considering the individual's social goals when assessing communication skills and creating individualized education plan (IEP) goals. Additionally, the study provides information regarding the social outcomes of a sample of individuals representing various regions of the United States.

Future studies should utilize larger samples of parents and caregivers. To further explore the communication needs of transition aged youth with autism, it would be essential to obtain information from all the key stakeholders of this population including: the individuals themselves, special education teachers, speech language pathologists, occupational therapists, and employers. After determining the most essential areas of need, an intervention approach that targets these areas could be developed. To determine if improvement with these skills leads to better social outcomes, a sensitive measure that detects small improvements in communication skills should be utilized.

Regarding speech pathologists, it would be beneficial to investigate the number of speech pathologists working with this population and which assessment and intervention techniques they are utilizing. Ehren (2000) noted there is a need for speech language

pathologists to advocate for high school students with language and learning disabilities. SLPs also need to educate teachers and other professionals regarding the communication needs of secondary students with autism and the role of the SLP in assessment and treatment of individuals with autism.

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